

## September 7, 2005 Testimony by Kolleen Stacey

I am very honored to be here today to speak to you about something very dear to my heart...Johanna's Law.

Last year I went to an Advocacy Training Meeting and heard Sheryl Silver speak about her sister Johanna and her motives for Johanna's Law. That speech gave me Hope that someday something will be done to make women and health care professionals more aware of the signs and symptoms of gynecologic cancers.

Sheryl, I want to thank you so much for taking the initiative to propose a bill long overdue. Johanna's story and mine were so much the same that it gave me cold chills. Unfortunately, thousands of other women have the same story...caused in great part ... by a lack of knowledge of the symptoms of Ovarian Cancer. The need for education and awareness is crucial. Johanna's Law will provide a campaign that will definitely save lives.

For the last 8 years I have suffered through numerous surgeries, recurrences and countless hours of chemotherapy and radiation. Why? Could this suffering have been prevented or at least lessened? I learned after diagnosis that I had all the symptoms. I wasn't aware that indigestion, heart burn, pressure on your bladder, unusual bleeding were symptoms of Ovarian Cancer. Nor did I know that a PAP smear test did not screen for Ovarian Cancer. I visited doctors for each of those symptoms, but no one put it all together! It took an entire year before I was diagnosed correctly. By then the cancer was stage 3C, an advanced stage of ovarian cancer with only a 38% chance of complete cure. Had the cancer been discovered in an earlier stage I would have had a 90% chance of complete cure!

Today, eight years later, nothing's changed. I am still meeting women who did not learn about the signs and symptoms until after diagnosis. Together, we can change this.

I may look good to you today...at least I hope so. However, that hasn't always been the case. Time won't permit me to go into great detail of all my experiences over the last eight years. But, let me tell you what I have gone through this year alone. I had a PET scan last December that showed a tumor in a lymph node in my neck. Surgery was scheduled for January to remove the tumor. It turned out to be much worse than the doctors expected. On January 7, I woke up with incisions up and down and across my neck that were stapled together. I also had 2 drainage tubes and 6 radiation catheters hanging out of my neck. I could tell people were frightened and shocked by the way I looked. My friends said "you have a good Frankenstein look going Kolleen." I saw the fear in my family's eyes and I was immediately scared too. I was then told my cancer had spread and the surgeons had to remove two nerve clusters and my jugular vein.

Four weeks after surgery and radiation treatments, a follow-up PET scan was done. My cancer had spread. We had no choice but to be aggressive with treatment. I felt like giving up.

This is not fun! My family is tired of seeing me with pain. I have multiple side effects that will be with me the rest of my life. My quality of life has dramatically changed. I have an equilibrium problem that makes me unable to walk alone unless I have sufficient lighting. I have numbness in my feet and hands; continuous pain; constant fatigue; and I was forced to go on disability. Being on disability affects my pride. This year, the eighth year, I wanted to give up, but I knew I could not. I have to fight for my family and to save other women from going through this horrible experience. Cancer is not just a physical condition but also an emotional roller coaster for me, my family, and my friends. I could not have done it without their love and support.

In closing, I would like to leave you with a feeling of hope. As children, we hope to grow up to be big and strong. As adults, we hope to be healthy and live a long happy life. If we are not healthy, we hope that our experience will help the people around us to make the right decisions. By passing Johanna's Law, each of you has the chance to make the right decision and give HOPE to me, women, and grieving families who have been victims of these deadly cancers.

This year 28,000 women will die from a gynecologic cancer.

Thank you.